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ABSTRACT

This report describes the results of three studies of Canadian mothers with preterm infants that support three conclusions about mothers' experiences of preterm birth. The first conclusion is that preterm birth is a very stressful experience, even for mothers with relatively healthy infants. Mothers' major concerns focused on their infants' survival and need for special care, and their own alienation from a sense of being a mother. The second conclusion is that the nature of the stress and the focus of worry changes with the infants' recovery and development. At five months after discharge, the only difference between preterm and full-term mothers on a mood inventory was that preterm mothers saw themselves as less clearheaded than full-term mothers. Interview and questionnaire data indicated a decrease in stress. Concerns about the infant's survival and the mother's alienation from the maternal role were no longer salient issues. There were no perceived differences between preterm and full-term mothers in the parental role as assessed on the Parenting Stress Index. The third conclusion is that the magnitude of the stresses appears to dissipate over the infant's first year. Preterm mothers in the second study were still worried about their infants' development and recognized the vulnerability of their infants, and thus the ongoing need for special care. The paper also includes discussion of the aims of the neonatal intensive care unit in which the research was conducted. Eight graphs and the maternal discharge questions are attached. (RH)

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MATERNAL EMOTIONAL RESPONSES TO PRETERM BIRTH

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Maternal Emotional Responses to Preterm Birth

This afternoon I want to describe the results of three studies of mothers with preterm infants that support three conclusions about mothers' experiences of preterm birth. The first conclusion is that preterm birth is a very stressful experience, even for mothers with relatively healthy preterm infants. Conclusion two is that the nature of the stress and the focus of worry changes with the infants' recovery and development. The third conclusion is that the magnitude of the stresses appear to dissipate over the infant's first year. I believe this third conclusion is in contrast to the findings that will be presented by my colleagues in this symposium. .

Before presenting the data, I need to describe our setting. The social context of preterm birth may be different between our sample and the samples to be described by my colleagues. Our NICU is a regional tertiary care centre serving southwestern Ontario, Canada. This region has approximately 20,000 births annually. The infants in our samples were inborn and the NICU is in close proximity to the birth and postnatal area, facilitating early and regular maternal contact regardless of the infants' illnesses. The infants' parents, siblings, grandparents, and supportive friends were actively encouraged to visit at any time. Our samples were drawn with the restrictions that the infants had no gross neurological or physical anomalies at birth, and that the mothers spoke English and lived within 100 km of the hospital.

This population may differ in many important ways from the populations sampled by my colleagues - I would like to point to two differences. First, as illustrated in SLIDE 1, preterm birth is independent of the mothers' socio-demographic context. This slide is a birthweight by maternal education scatter plot, the STARS represent preterm mothers and the OVALS represent full term mothers. Note that education is independent of birthweight both within

and between the two samples. In all three studies that I will describe, indices of the infants' biomedical condition such as birthweights, gestational ages, neonatal morbidity, or the length of the infants' hospitalization are independent of indices of the families' social-demographic context such as maternal ages, education, paternal education or family incomes. A second potential sample difference is that this population of mothers is remarkably free of cocaine use; only one admission to the NICU over the past 10 years has been diagnosed as related to cocaine.

Study 1. [This is a sub-sample of the paper reported by Pederson, Bento, Chance, Evans & Fox (1987). The sample in the previous paper included infants with birthweights up to 2500 grams. The present paper focuses on the very low birthweight (i.e., < 1500 g) infants in the Pederson, et al, 1987 sample.]

It was not our intention to study the emotional impact of preterm birth in our first study. We were interested in parental factors that were associated with the social and intellectual development of preterm infants (Pederson, Evans, Chance, Bento, & Fox, 1988). We interviewed the mothers shortly before the infants' hospital discharge mainly to get information about her social support systems. We also asked mothers to describe what it was like to have a preterm baby.

I must confess, I was not prepared for the answers! In the early 1980's, you may recall, mothers of preterm infants were depicted as immersed in grief about their own biological inadequacies and about the full term baby they didn't have (Caplan, 1960; Kaplan & Mason, 1960; Klaus & Kennell, 1976) and, judging from the low visiting rates (Barnett, Leiderman, Grobstein & Klaus, 1970), unconcerned about their real infant.

The medical and demographic background of the 55 mother-infant dyads in

this study are presented in Slide 2. Note that these infants were born in 1982-1984. The infants' gestational ages ranged from 25 to 35 weeks; their birthweights from 460 to 1480 grams. Both the mothers and fathers had an average of a grade 12 education. The interview transcripts were coded for the presence or absence of 11 categories of emotional stress and worry. These categories are described in Slide 3.

1. Emotionally upset - feelings of sadness, shock, crying; difficulties in functioning such as anxiety or insomnia. To be scored, the mother explicitly described feelings of shock, anxiety, or crying.

2. Crying - crying during the interview; mother reported that she could not stop crying during the first few weeks after her infant was born.

3. Worries about infant's Survival -

4. Worries about infant's physical and/or mental development - concerns about long term prognosis, uncertainty that infant would be physically or developmentally normal

5. Anticipated need for Special Care - infant would need more physical care and monitoring that expected with a full term infant; anticipated need to be protective because of infant's vulnerability

6. Alienation from sense of being a mother - feeling of helplessness because she had no control over infant's care or well-being; feeling that infant was not hers; not feeling like a parent

7. Difficulties in Visiting - Difficulties arranging transportation to visit infant or getting child care for siblings at home

8. Disappointment - expectations about baby not fulfilled - e.g., expected a cute cuddly baby; baby did not look like a baby

9. Guilt - feeling responsible for prematurity, guilt over what baby is going

through.

10. Psychosomatic symptoms - feeling physically ill at the thought of visiting her infant; feeling faint or other physical symptoms which would make it difficult to visit.

11. Resentment - at being separated from her baby - feeling envious of mothers who had experienced normal birth, anger at hospital staff for placing her in a room where other mothers had their infants with them.

The classification percentages are presented in Slide 4. Almost all mothers were emotionally upset. Thirty-six percent reported that they could not stop crying during the first weeks of the babies' lives. Mothers anticipated that their babies would need special care after discharge and were concerned with their infants' survival . About 30% of the mothers reported feeling responsible for their infants' condition and their suffering (GUILT). Notice that the focus was, rather realistically, on the infants' survival and needs for special care and her alienation from the maternal role - probably a reflection of the mother's feeling that she could not do anything to help her baby. Self-directed concerns such as feelings of guilt, psychosomatic symptoms and resentment over being separated from her infant were not as frequent.

We also generated a summary stress score as a reflection of the over all stress described by mothers. To produce this summary stress score we cumulated the frequencies of coded stress in these categories. This aggregated variable is moderately correlated with birthweight, gestational age, length of infants' hospital stay and severity of the infants' neonatal medical course (r's range from .35 to .41). These findings are illustrated in Slide 5 which is a Stress by Birthweight scatter plot (the scatter plot for

the other indices of biomedical risk are similar, I chose birthweight for illustrative purposes because it is a familiar variable). As would be expected, emotional stress is related to variations in the infants' biomedical risk (in this case r = -.37); however, it is important to note that many mothers of larger very low birthweight infants also reported considerable stress (point to the similarities in stress scores between 460 and 1470 grams). Emotional stress appears to be related as much to the fact that their infants require NICU care as it is to the severity of the infants' biomedical risks.

Study 2.

We pursued these findings in a second study. Thirty-five mothers with preterm infants born in 1986-1988 were interviewed and completed questionnaires shortly before their infants were discharged from the hospital and 5 months later. The preterm infants' birth weights averaged 991 g (range = 550 to 1470 g) and gestational ages averaged 27.4 weeks (range = 23 to 33 weeks). We also recruited a comparison group of mothers of full term infants matched for infants' sex and birth order. In the interviews, the mothers were asked about the differences in experiences from those anticipated with a full term birth, their feelings and concerns about their babies, and if they anticipated that their infants would need special care after discharge. We attempted a similar interview with the full term mothers, but the issues were very different for them so a comparable interview was impossible. As shown in Slide 6, 91% of the mothers were emotionally upset, 61% reported they could not stop crying, in fact about a quarter of the mothers wept during the interviews. As in the first study, the mothers' main concerns were about the special care their babies may need, their infants' physical survival, and

their alienation from the maternal role. In the interviews at five months' post-discharge most of the reported stresses had diminished. Worry about the infants' survival and alienation from the maternal role were no longer salient issues. However, many mothers were still concerned about their babies' physical development. They also reported differences in caring for their premature babies and disappointment when thinking about their babies' birth.

We wanted to document the emotional stress with a standardized questionnaire that would enable a comparison with mothers of full term infants. We choose the Lorr & McNair (1982) Profile of Mood States, bi-polar version. The dimensions assessed seemed relevant to the experiences of new mothers. The respondent is asked to indicate how much her current feelings are like each mood. The Profile of Mood States lists 72 adjectives such as composed, angry, cheerful, tired, powerful, and inadequate that are classified into six bi-polar states as illustrated in SLIDE 7: composed-anxious, agreeable-hostile, elated-depressed, confident-unsure, energetic-tired, and clearheaded-confused. The questionnaire was administered shortly before the infants' discharge thus about 2 days post-delivery for the full term mothers and an average of 72 days post-delivery for the preterm mothers. The means for the standardized scores on the Profile of Mood States for the two groups at the time of hospital discharge are presented in Slide 7. On the Profile of Mood States, the standardized mean is 50. The two groups of mothers differed significantly on three of the six scales. The full term mothers were more Composed, Elated and the Clearheaded than the preterm mothers. At five months' post discharge the only significant difference was that full term mothers were more Clearheaded than the preterm mothers. The increases in Confidence, Energy, and Clearheadedness were significant for both groups of

mothers. As well, preterm mothers became significantly more Composed and Elated. (Note adjectives on the Clearheaded-Confused scale include confused, clearheaded, mixed up efficient, bewildered, attentive, perplexed, able to concentrate, muddled, businesslike, dazed, and mentally alert.)

For Study 2 we developed a questionnaire in which mothers were asked about their experiences. The items sampled content areas which were identified by the mothers in the interviews in Study 1. Full term mothers were given a parallel questionnaire in which questions about the experiences in the NICU were omitted. At the time of hospital discharge, preterm mothers rated themselves as crying more and feeling more disappointment with the events surrounding their babies' birth than full term mothers. They also felt more helpless about their babies' care and were more worried about future pregnancies. At the time of their babies' discharge preterm mothers did not differ from full term mothers on items about feeling sad when thinking about their baby or with coping with motherhood. See Slide 8. At 5 months post-discharge, the preterm mothers reported more crying about the baby, disappointment in recalling baby's birth, and worry about future pregnancies.

Thus, the interview and the Profile of Mood States data indicate that the general feelings of stress and worry have diminished for preterm mothers over the five months since discharge. The need for special care and apprehension about their babies' physical development continue to be major concerns for these mothers.

Study 3. I can be very brief about our current study. This is a sample of preterm and full term mother infant dyads. The infants were born in 1989-1991. The sample characteristics and the interview, Profile of Mood States and Questionnaire data are essentially identical to our earlier studies. When

their infants are eight months old, mothers are asked to describe the stresses of parenting by completing the Parenting Stress Index (Abidin, 1986). In the Parenting Stress Index, mothers rate the stresses related to child characteristics that challenge the parenting role (SLIDE 9). The subscales on this Child Domain include the child's adaptability, demandingness or bother, mood, distractibility and reinforces parent. Higher scores represent more stress. As you can see from Slide 9, there are slight tendencies for preterm mothers to have higher stress scores, although the differences are small and with the exception of the acceptance sub-scale, statistically non-significant.

Other items on the Parenting Stress Index focus on mothers' characteristics and circumstances that interfere with her parenting role (SLIDE 10). Subscales on the Parent Domain scale include depression, role restrictions, parenting competence, social isolation, spousal relationships and parental health. As you can see from Slide 10, there is almost complete overlap between preterm and full term mothers. These results are consistent with our conclusions that the stresses associated with preterm birth decrease over the months after hospital discharge.

Conclusions.

1. Preterm birth is an emotionally stressful experience for mothers. Their major concerns focus on their infants' survival, need for special care, and alienation from a sense of being a mother.

2. The intensity of stress abates after discharge. In Study 2, at 5-months post-discharge the only difference between preterm and full term mothers on the mood inventory was that preterm mothers saw themselves as less clearheaded than full term mothers. The interview and questionnaire data also indicated a decrease in stress. Concerns about the infants' survival and alienation from

the maternal role were no longer salient issues. Similarly, there were no perceived differences between preterm and full term mothers in the parental role as assessed on the Parenting Stress Index.

3. Although the stresses have decreased in intensity, there were residual effects. Preterm mothers in Study 2 were still worried about their infants' development and recognized the vulnerability of their infants - thus the ongoing need for special care. Although the differences on the Child Domain of the Parenting Stress Index are small, there is a tendency for fullterm mothers to find their child as more acceptable than preterm mothers.

Changing face of neonatology.

Finally, we wish to comment on changes and continuity in the experiences of preterm mothers over the past decade. First, the changes. One impact of our research has been to remind NICU staff about the stresses faced even by mothers of relatively healthy infants. Our policy of open visiting and, with the parents' consent, of sharing medical progress with the infants' grandparents or other significant support person is an active effort to encourage the effectiveness of the mothers' emotional support systems. We are also addressing issues of alienation from maternal role by encouraging the mothers to become involved in the care of the infant as much as possible. Once their infants are over 800 g and in stable condition mothers are encouraged to hold their infant with the infant's temperature being maintained by radiant heat lamps. The mothers role in providing breast milk is emphasized as something that only she can do.

Second, we are impressed that the issues for preterm mothers remain the same. Preterm mothers today seem just as focused on their infants' survival, just as estranged from their maternal role and feel just as guilty as our first cohort

of mothers that we interviewed almost a decade ago. These are realistic reactions in response to concerns over the survival of a very vulnerable infant. Our goal is not to eliminate this pain, but to provide a humane and supportive environment that will allow the parents to deal with the anguish effectively so that this grief will not interfere with the processes of becoming effective parents.

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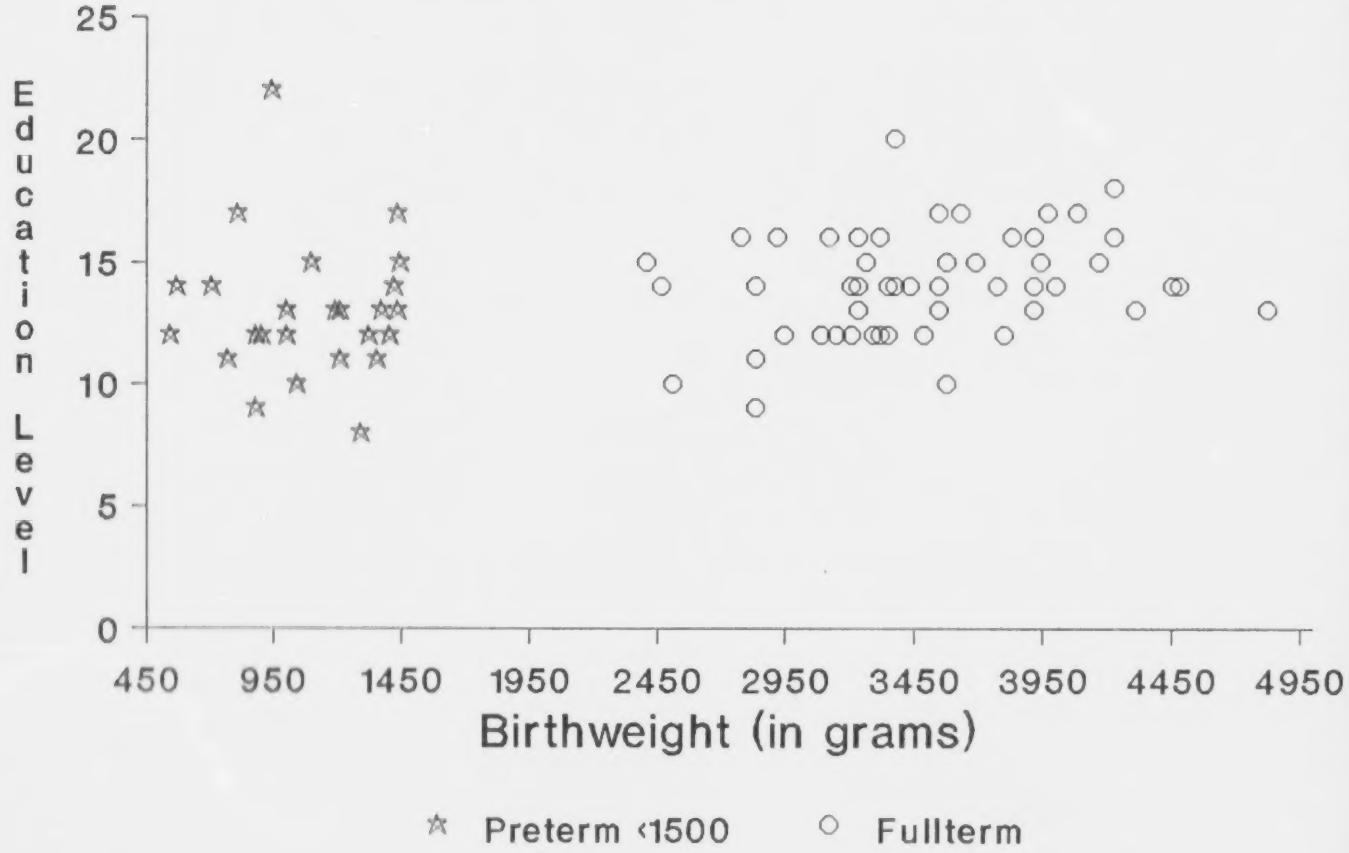
Maternal Education by Birthweight



Biomedical and Demographic Data from Study 1

Infants born between August, 1982 and August 1984

	Mean	S.D.	Minimum	Maximum
Birthweight (grams)	1081.5	256.7	460	1480
Gestational Age	28.6	2.3	25	35
Days in Hospital	75.4	32.1	26	181
Maternal Age	28.6	4.5	19	36
Maternal Education (Yrs)	12.0	2.1	8	17
Paternal Education (Yrs)	12.0	2.8	6	20

Categories used to code the interviews

1. **Emotionally upset** - feelings of sadness, shock, crying.

2. **Crying**.

3. Worries about infant's **Survival**.

4. Worries about infant's physical and/or mental **Development**.

5. Anticipated need for **Special Care**.

6. **Alienation** from sense of being a mother.

7. Difficulties in **Visiting**.

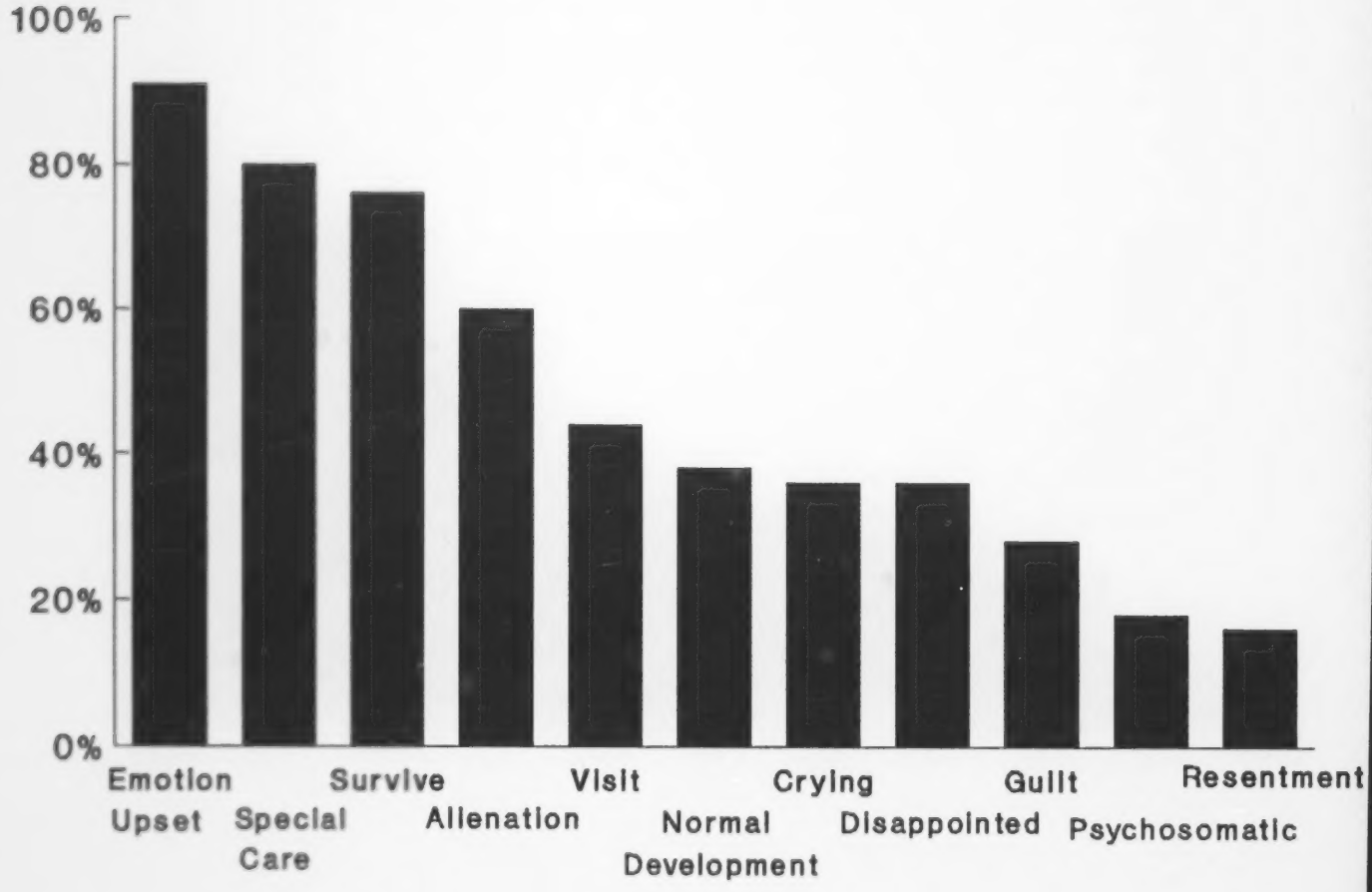
8. **Disappointment** - expectations about baby not fulfilled.

9. **Guilt** - feeling responsible for premature birth.

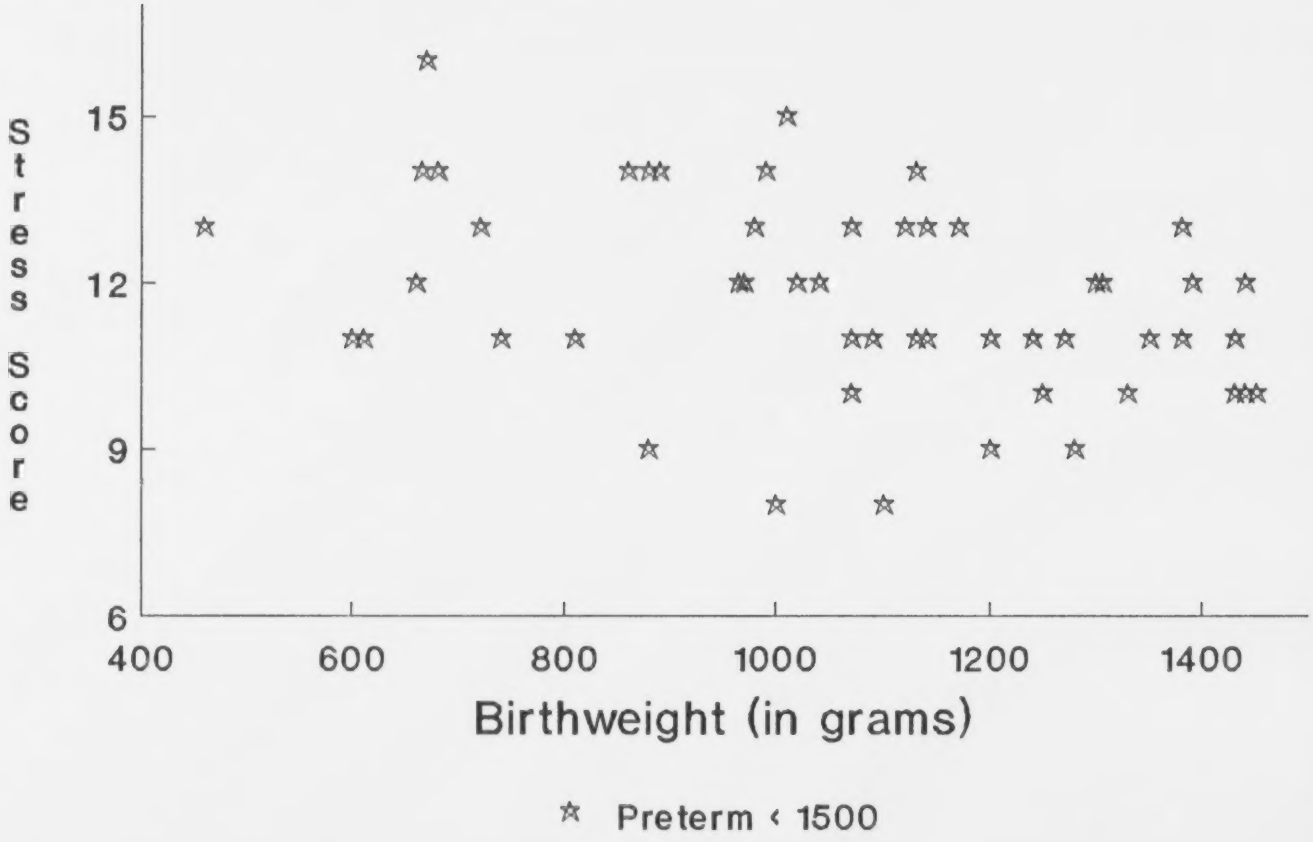
10. **Psychosomatic symptoms**.

11. **Resentment** - at being separated from her baby.

Maternal Emotional Responses
to Preterm Birth

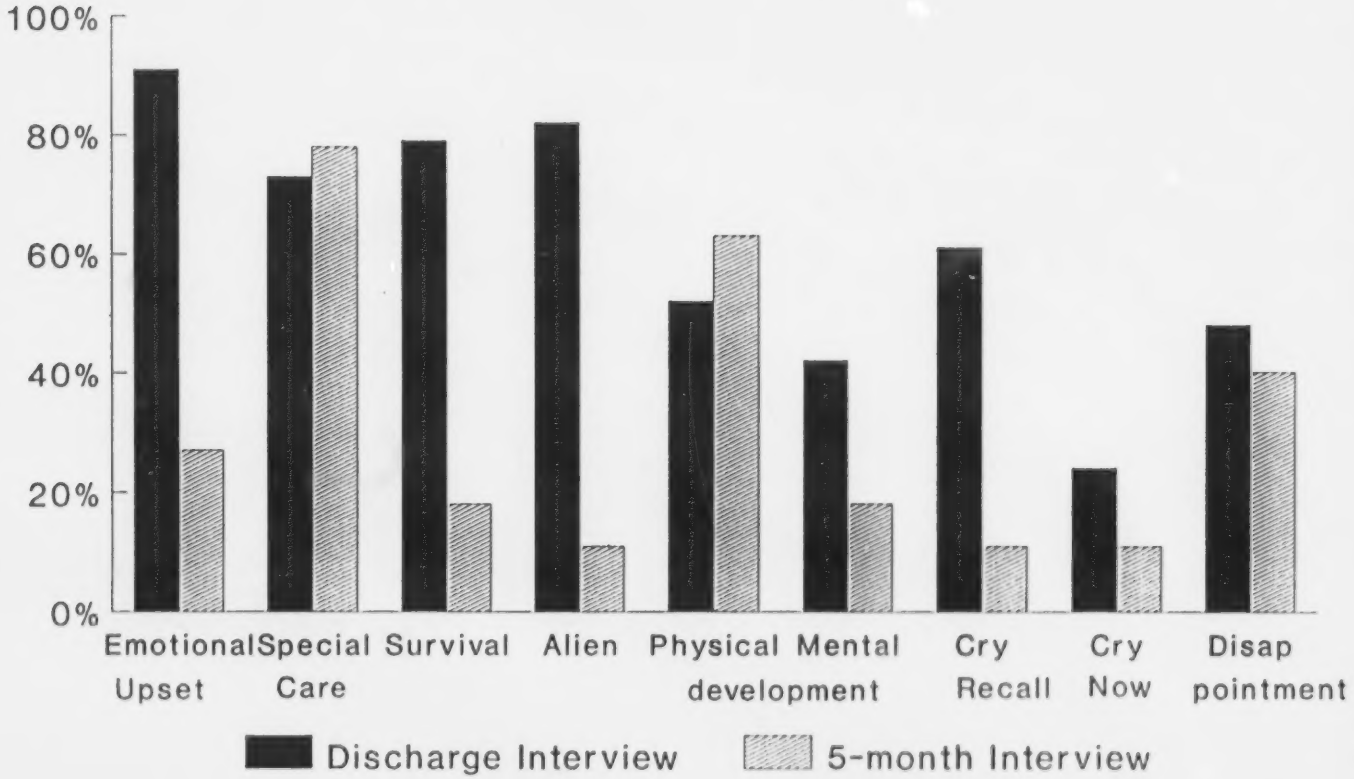


Stress by Birthweight Scatterplot

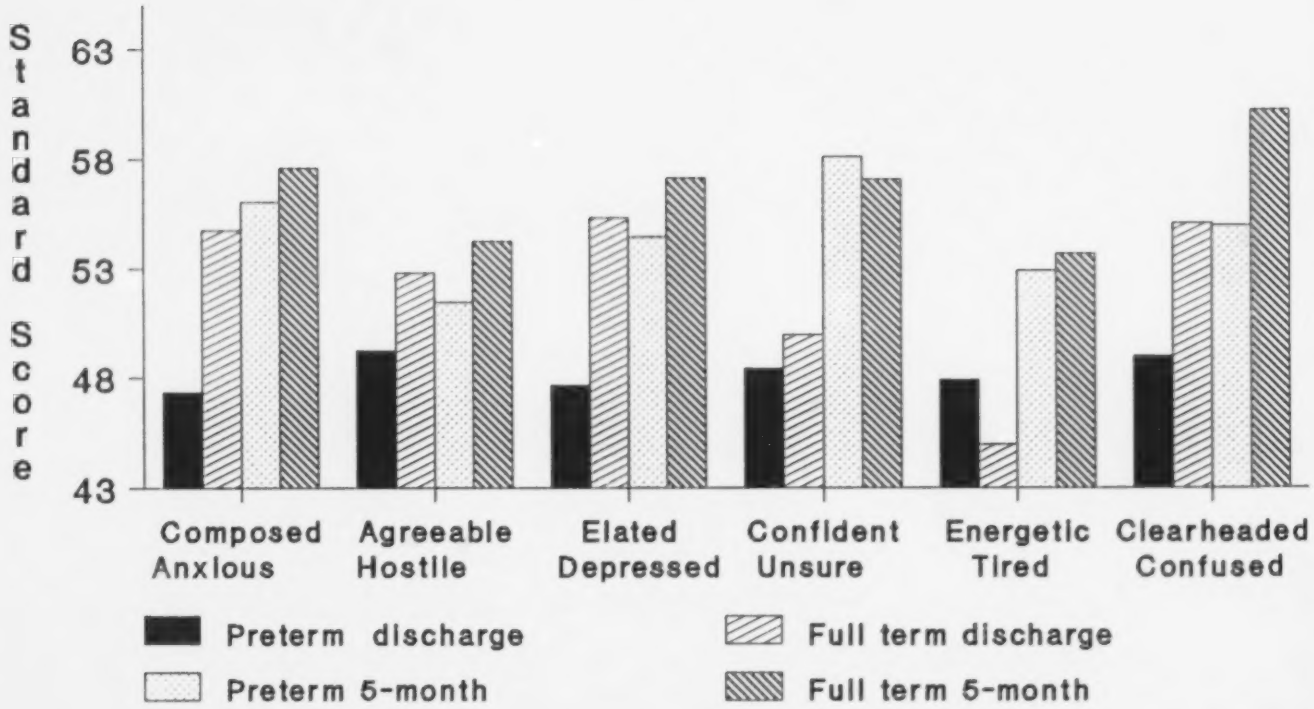


Stress of Preterm Birth

Study 2

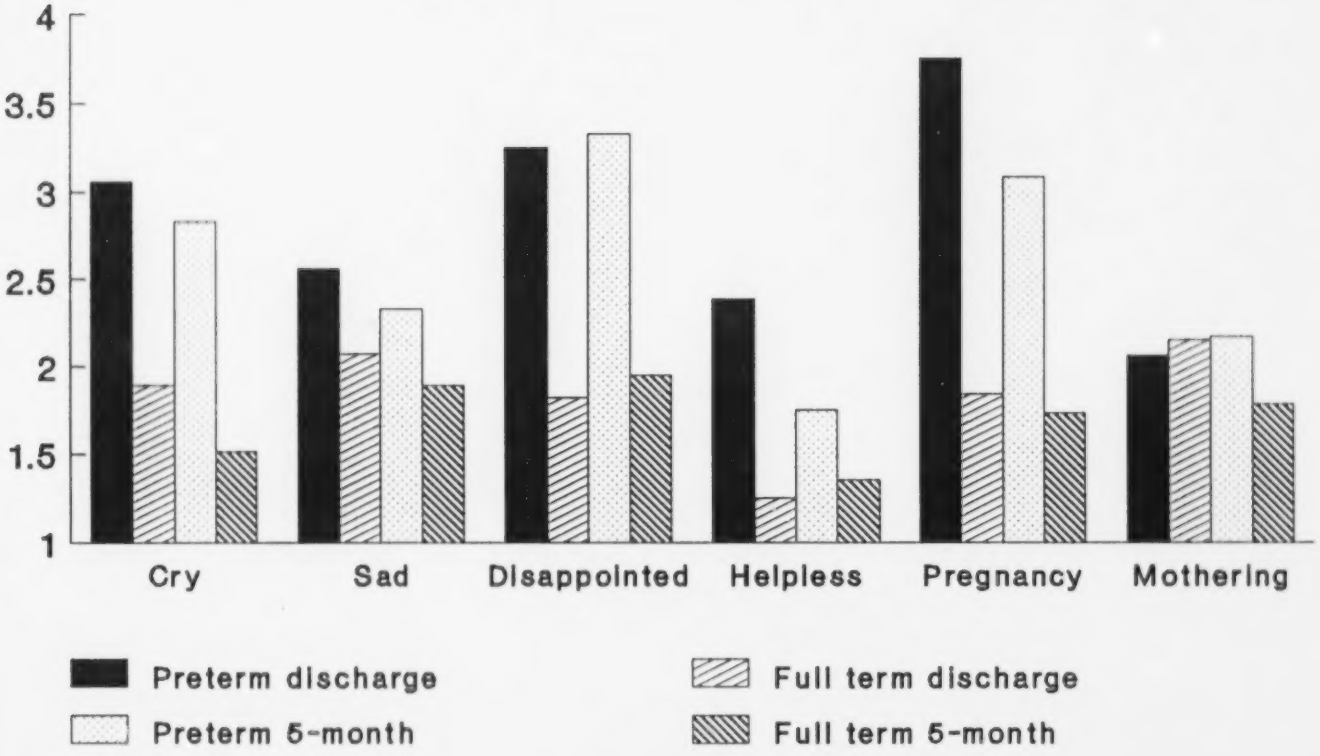


Profile of Mood States
Preterm and Full Term Mothers

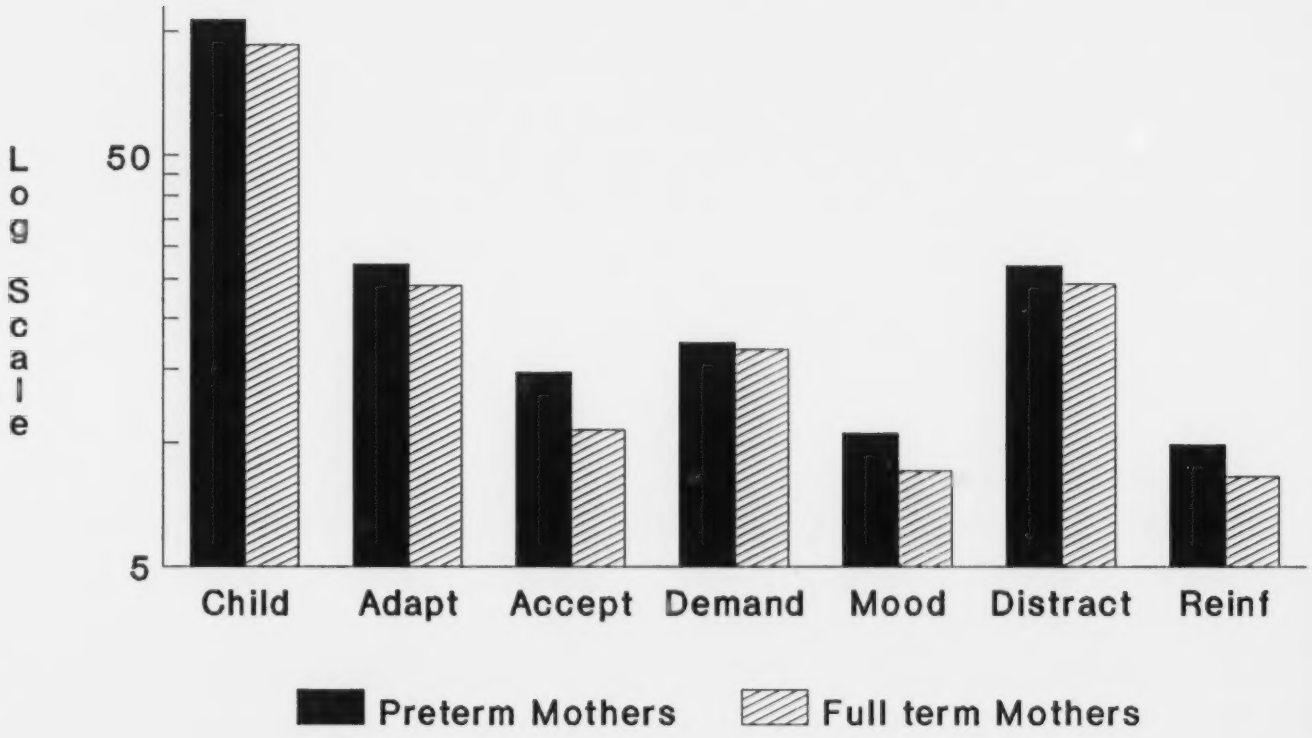


Parenting Questionnaire

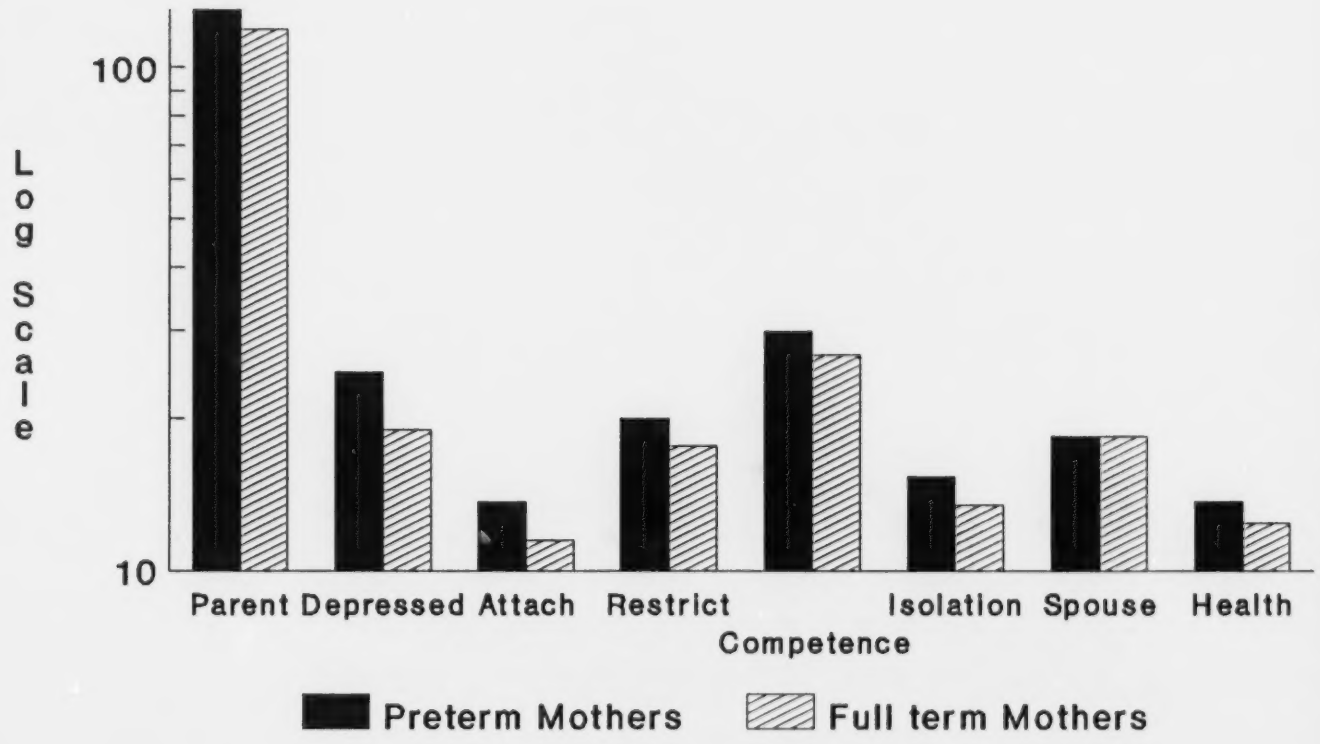
Emotional Upset Items



Parenting Stress Index
Child Domain



Parenting Stress Index
Parent Domain



Conclusions.

1. Preterm birth is an emotionally stressful experience.

2. The intensity of stress abates after discharge.

3. Residual stresses of preterm birth.

Maternal Discharge Interview

We would like to know how parents have coped throughout their infant's hospitalization.

1. How would you describe the differences in your experiences from what you expected? Do you see this experience as more stressful than what you anticipated ? Did you anticipate any of these differences? What are the differences that are concerning you?

2. How would you describe your feelings and concerns at this time?

3. Have you had a chance to really talk to the nurses and doctors taking care of your baby? (Do you feel you have been adequately informed of everything going on with your baby?)

4. We would like to talk to you about how your family and friends have been since your baby was born. What have you found to be most valuable in terms of support or helping you get through this time? (Do you see confiding in someone as a form of emotional support? Do you feel receiving information or child care assistance important sources of support?) Are there people you are able to confide in, or share your concerns and any fears with Who do you see as your major source of comfort and support?

a) How would you describe your husband's reactions to your premature baby? In what ways are they different fron your own?

b) How have your parents reacted? What about your other family members?

c) How have your in-laws responded?

d) Have your friends been involved in any way?

e) Have your neighbors been involved in any way?

f) Are you a member of any church or other spiritual organization? Have they been involved since your baby's birth?

g) Have you talked with anyone from the parent's support group?

h) Are there any other persons that have been a support to you since your baby's birth?

5. What has been most difficult for you since your baby was born? Do you feel any differently as a parent than what you had expected? Do you feel any differently toward the baby than what you had expected?

6. We are interested in your assessment of your baby's illness since yor baby's birth. How would you rate the severity of your baby's condition(If you think of the baby's entire hospitalization)

1 - Baby was essentially well: was admitted to the N.I.C.U. only for observation.

2 -

3 - Baby was small at birth ; needed to be in the N.I.C.U. for supportive treatment such as intravenous therapy, feeding, temperature regulation.

4 -

5 - Baby was ill, needed medical intervention in the N.I.C.U. but condition was not life-threatening.

6 -

7 - Baby was critically ill; treatment in the N.I.C.U. was essential.

7. Did you have any difficulty arranging visits to your baby? (geographic,babysitting, transportation,illness, financial)

8. Do you anticipate any differences in caring for your baby once he/she is home? How long do you expect these differences to last? Are there any differences that are concerning you?

9. Are there any special preparations you have made for your baby's homecoming? Will you be returning to work? Have these plans changed because your baby came early? What medical follow-up will you be involved in with your baby?

10. How do you think your baby is doing now that he/she is almost ready to go home?